# A qualitative exploration of the language and expression of pain in a Cape Town Emergency Centre

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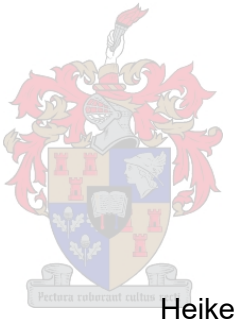

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# List of Abbreviations

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ATLS | Advanced Trauma Life Support |
| BTS | British Thoracic Society |
| EC | Emergency centre |
| HIC | High-income countries |
| HIV | Human Immunodeficiency Virus |
| ICD | Intercostal chest drain |
| LMIC | Low- and middle-income country |
| MPH | Mitchell's Plain Hospital |
| NCD | Noncommunicable disease |
| NRS | Numeric Rating Scale |
| PEMI | Pain and Emergency Medicine Initiative |
| TB | Tuberculosis |
| VRS | Verbal Rating Scale |
| VAS | Visual Analogue Scale |
| WHO | World Health Organisation |

# Part A: Literature Review

## Objectives of literature review

To fully understand the intricacies of how patients express their pain in Emergency Centres (ECs) in the South African setting, the following objectives have been identified to guide the literature review:

- To understand the epidemiology of pain, as a presenting complaint, in emergency centres.
- To understand the benefits of adequate analgesia in emergency centres.
- To investigate potential barriers to adequate analgesia in emergency centres.
- To explore current practice to assess pain in emergency centres, including the use of pain scales.
- To identify whether the current practices for assessing pain can be extrapolated across cultures, particularly in low- and middle-income (LMIC) settings.
- To investigate the severity of pain associated with tube thoracostomy, and the expression thereof.
- To explore the relationship between culture and expression of pain in emergency centres.
- To explore the value of using patient narratives as a tool to understand the experience of pain.

## Literature search strategy

English language studies in peer reviewed journals were sought through searches of online databases, namely PubMed and Google Scholar.

The MeSH terms used were “expression of pain”, “analgesia”, “pain assessment”, “culture and pain” and “language and pain”. The MeSH terms were used in multiple variations with the following other terms – “tube thoracostamy”, “oligoanalgesia”, “pain scales”, “emergency centre”, “tube thoracostomy” The term “emergency centre” was alternated and substituted with the terms “emergency department” and “trauma unit”. The term “tube thoracostomy” was alternated and substituted with the terms “intercostal chest drain” and “chest tube”.

The studies were identified from the search results, were reviewed separately. Relative studies were then explored. Only studies published in English in peer reviewed journals, where full text articles were freely available via the university library portal, were included. Additional studies were identified through scouring the references of the already recognised studies as

pertinent for inclusion. No time filter was applied to the search criteria as a paucity of literature exists that addresses this topic.

No formal critical appraisal of the quality of the articles referenced was undertaken, as this is beyond the scope of the Masters of Medicine (MMED) thesis.

# Summary of literature

## Pain in the Emergency Centre

Pain affects the majority of patients presenting to emergency centres (ECs).[1,2,3] Johnston, in 1998, estimated over 50% of patients, both adults and children, complained of clinically significant pain on EC admission.[1] Similarly, in 2003, Cordell found a high prevalence of pain at presentation in an American EC, with over 61% of patients having pain. It was further noted that pain was the primary complaint in 52% of the presentations.[3] The Pain and Emergency Medicine Initiative (PEMI) multicentre study across North American ECs, noted that pain intensity at presentation was severe (median 8/10).[2] They further noted that while initial pain assessments were common, re-evaluation of pain was uncommon. Only 60% of these patients in pain received analgesia and usually after a lengthy wait. They concluded that EC pain is common, its intensity severe, analgesia under-used and delays to analgesia common.[2]

The epidemiology of pain in the EC in low- and middle-income (LMIC) settings, has been less frequently researched. However, a study conducted at a Nigerian academic hospital found that pain scores for surgical presentations, predominantly trauma-related, were high (median 6.9/10). They further found that 45% of these patients were not offered analgesia, including the majority of those in severe pain (Visual Analogue Scale score >7.5/10). Of those who were given analgesia, 81% continued to have moderate to severe pain. This translated to almost all (30/31) of the patients with severe pain being dissatisfied with the care received.[4]

Trauma, particularly in low- and middle-income settings contributes significantly to emergency presentations.[5] Pain is a predominant feature in most trauma presentations.[6]

A study conducted at a Cape Town paediatric trauma unit found that while pain and anxiety scores were generally low, only two-thirds of patients were offered analgesia- and less than 60% of those who had moderate to severe pain.[7]

## The value of adequate analgesia

Optimal pain management is noted to increase patient satisfaction, positively influence the doctor-patient relationship and decrease patient distress.[8] The World Health Organisation (WHO) has decreed pain management as a human right.[9] Yet, *oligoanalgesia* - failure to recognise or treat pain - in the EC is increasingly being acknowledged.[10,11] Todd's pan-American EC study found that 74% of patients were eventually discharged with pain scores in the moderate or severe category.[2] Fosnocht has postulated that emergency provider focus has shifted to finding and managing the cause of patient pain as opposed to treating the underlying pain itself, despite pain being the reason for presentation.[12]

Pain is associated with both an unfavourable physiological and as well psychological healing response. Thus, poorly managed pain contributes to impaired return of function.[13]

Physiologically, pain serves as an indicator of tissue damage. It is a symptom of an underlying pathological process.[14] Pain thus plays a role in seeking medical help for underlying medical conditions.

It has been suggested that pain alters normal physiology. Greisen, demonstrated a neuroendocrine shift as a result of pain, in a sample where injury or tissue damage was absent.[15] Pain is also known to result in a release of proinflammatory cytokines, as demonstrated by various studies on surgical patients.[16–18] Similarly, pain increases one's sympathetic drive, increasing myocardial oxygen demand and decreasing gastric motility. Upper abdominal, or thoracic pain contributes to decreased coughing, atelectasis and subsequent hypoxemia.[19] This contributes to end organ dysfunction, and a potential for negative adverse outcomes. Adequate analgesia plays a role in reducing morbidity as demonstrated by decreasing the risk of cardiovascular, respiratory and gastrointestinal dysfunction.[20]

Pain is also acknowledged as being an unpleasant sensory stimulus.[14] Untreated pain is linked to negative emotional states including anger, depression, anxiety and fear.[21] The link between chronic pain and negative psychological consequences is well documented.[13] But, unmanaged acute pain results in a persistent nociceptive input which may impact psychological well-being. This negative psychological response is a key element in the progression to chronic pain.[13] Adequate pain management is associated with better patient satisfaction, as well as improved patient-physician rapport.[22,8]

## Culture and Pain

The relationship between culture and pain is receiving increasing scrutiny as societies are becoming more diverse as the global population expands. No longer are physicians only treating patients from a similar background to theirs, thus cultural sensitivity is now required more than ever to treat the patients from ever-evolving diverse backgrounds.

The association between demographic factors and oligoanalgesia have also been documented.[23] Todd, in two separate studies, has demonstrated ethnic minorities in an American population receive less analgesia than their white American counterparts.[2,24] Similarly, gender and age bias with regards to analgesic prescription have been shown to exist, with males and non-elderly patients susceptible to suboptimal analgesia practises.[25,26]

Pain is subjective and its perception and expression is influenced by an interplay of multiple physical, psychological and social aspects including genetics, previous experience, emotions, age, gender and culture.[27,28]

While many clinical and laboratory studies aimed at determining the role of ethnicity in pain have suggested that ethnicity may have a role in how pain is perceived and how it's expressed, the results aren't entirely conclusive.[29] These inconsistent results are often as a result of methodically poor studies.[28] Further, more rigorous research is required to assess the effect of culture on pain perception and expression.

Healthcare worker associated bias plays a part in differing analgesia practises across cultures. Minority status often reflects a cultural difference from the healthcare provider.[28] Bernabei explored the pain management of elderly cancer patients, and found that belonging to a minority race was an independent predictor of not receiving any analgesia.[30] Cleeland similarly found that 65% of minority oncology patients who had pain had received an inadequate analgesia prescription, compared to 50% of their nonminority counterparts.[31]

Todd focussed three of his studies on ethnicity and analgesia practise, specific to the EC. In 1993, he found that Hispanic patients in a Los Angeles EC were more likely to receive no analgesia when compared to similar white patients.[24] In 1994, however, he noted in the same EC that while physicians underestimated patient pain experience, this underestimation was equal across the Hispanic and non-Hispanic population.[32] In 2000, he noted a significant difference in analgesia practise between black and white patients with isolated long bone fractures. In this study, after controlling potential cofounders, he found that white patients were more likely to receive analgesia despite similar pain profiles.[33]

All these studies are from a high income setting- United States. No similar adult studies in low and middle-income settings were found.[34]

Studies from Central Africa and Malawi reviewing nurses' beliefs regarding analgesia demonstrated that culture plays a role in medical professional training as well.[35,36] Nurses believed that opioids were bad, addictive and potentially deadly. [35,36] Some believes that treating pain may impede the healing process, pain was a result of weakness and that pain should be tolerated as it is a normal process that occurs with illness or injury.[35]

Biopsychosocial models of pain have been widely proposed as a means of understanding the factors that contribute to pain.[37] One such model, proposed by Petty and Moore, categorises factors contributing to pain into 6 dimensions as shown below.[38]

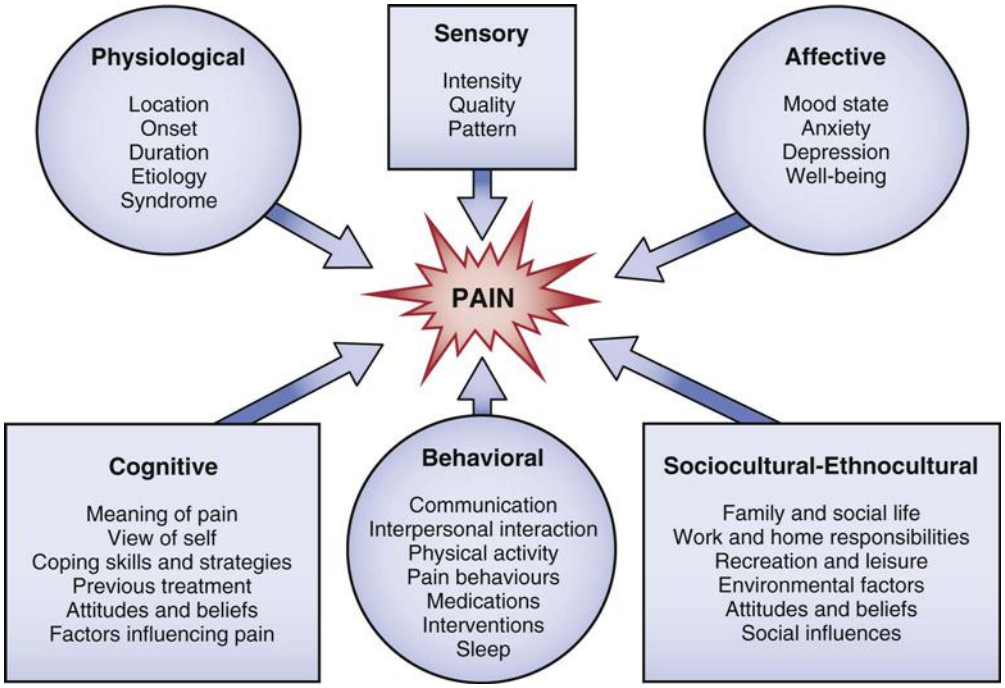


*Figure 1: The dimensions of pain (Petty and Moore)*[38]

## Barriers to adequate analgesia

A review of available literature demonstrates that oligoanalgesia is usually secondary to some, or combinations of the failure to acknowledge, assess or document pain; failure to assess response to pain treatment; failure to institute analgesia protocols in the EC and failure to meet patient expectations with regards to analgesic requirements.[23,39]

Current literature has noted physician related factors as barriers to analgesia.[23] This includes insufficient training in pain management received by emergency practitioners[40] and underestimation of patient pain by physician.[41] The concept of physician opiophobia is a concept that has been receiving much needed attention.[42] The portmanteau of the words opioid and phobia, refers to the irrational fear of opioids. Neighbor demonstrated underuse of opioids for trauma victims[43], while Bijur demonstrated that the widely accepted dose of 0.1mg/kg of morphine to be ineffective in controlling acute severe pain.[44]

While it's been recognised that pain affects a majority of EC patients, physician acknowledgement of patient pain is notoriously poor.[23] Todd's 2007 pan-American EC study found that 74% of patients were eventually discharged with moderate to severe pain.[2] A lack of acknowledgement, can be a direct result of inadequate assessment of pain. Guru and Dubinsky found that both nurses and physicians underestimated patients pain when compared to self-reports from patients.[45]

The emergency centre itself provided additional challenges to optimal analgesia practises. Hwang has demonstrated a 2-hour delay to analgesia in patients with hip fractures presenting to an EC caused by EC overcrowding (defined as over 120% capacity).[46] Similarly Pines and Hollander concluded that EC crowding resulted in delays or overall omission of pain management in patients with severe pain.[47]

Patient related factors are well known to play a part in inadequate analgesia practises in chronic pain.[48] However, a few studies looking at patient related factors for not using analgesia immediately before or during EC visits, despite its availability, found that fear of side-effects and fear of addiction were common.[49,50] Better patient education surrounding the use of analgesia is required to empower them to make decision regarding their analgesic options.

While most research regarding analgesia, or lack thereof, in the EC originates from hospitals in high-income countries (HICs), Olakulehin, through a Nigerian cohort, proposed that a significant discrepancy exists between patient and healthcare provider estimation of pain during painful emergency centre procedures.[51] Healthcare practitioners in Rwanda, had limited acute pain management training, with regards to post-operative surgical pain, and feared side effects of certain drugs.[52] This demonstrates similar barriers to analgesia in HICs and low- and middle-income countries (LMICs). More so, LMICs struggle with EC overcrowding[53] and this further compounds delays and limits the prescribing of analgesia and its administration.

A review article from a paediatric hospital in Cape Town suggested that African children are particularly susceptible to pain as Africa has almost a quarter of the global disease burden, yet only an insubstantial percentage of the healthcare workforce. Also, the majority of the countries that do not comply to basic health needs, are African. This leads too poorly managed pain in paediatric patients at this trauma centre.[54] Language barriers, cultural differences and lack of resources all were fundamental obstacles to treating patient pain.[54]

## Assessing pain severity

Acknowledging, assessing, documenting and assessing response to treatment of pain are fundamental in preventing oligoanalgesia and decreasing patient suffering.[23] The American Pain Society (APS) in 1996 began a campaign to consider pain as the ‘fifth vital sign’ in response to their quality improvement guidelines published.[55] This, as an attempt to emphasise the significance of adequate pain management, and to diminish the burden of oligoanalgesia that was beginning to be appreciated. They suggested that pain scales be used, and documented, and high scores on these scales being an urgent prompt for action.[55] In recent years however, the APS’s fifth vital sign campaign was increasingly being criticised

being as a direct contributor to the opioid addiction epidemic in HICs.[56] Despite this, it brought to the fore the need for assessment and documentation of patient pain, and stimulated research surrounding methods of pain assessment, including the value and validity of pain scales.

Pain assessment is multidimensional. Certain parameters are more easily assessed than others. Pain be described quite easily using basic language in terms of location or character, but determining severity of pain, is more complex.

Pain scales are central to the process of assessing pain severity. Pain scales used to determine patient experience of pain are commonly used in clinical medicine to improve analgesia practices.[57] Commonly, the Visual Analogue Scale (VAS), Verbal Rating Scale (VRS), Numeric Rating Scale (NRS) and the Wong Baker Faces Pain Rating Scale are used to assess pain in all medical departments including post procedural pain and pain the EC[58,59,60,61] While all have shown strong validity in clinical trials mostly in high income countries (HICs)[60], each have varying strengths and limitations. The VAS has infinite response categories, but is time consuming, requires extra steps and is slightly more complex to use for certain populations (e.g. the elderly).[60] The VRS is easy to use and score, but requires a vocabulary in the language it is being administered in, and only allows for a limited number of possible responses.[60] The NRS, has many (but not infinite) response categories, is easy to score but ratio data of responses cannot be calculated.[60] The Wong-Baker Faces Pain Rating Scale was initially developed for children due to its simplicity, but its validity has been proven in adult populations subsequently.[61–63]

Melzack and Torgerson acknowledged that the pain experience is more complex than can be assessed using a unidimensional scale.[64] The development of the McGill pain questionnaire was centred around the fact that pain that pain is a subjective experience, but required quantitative values to be managed statistically. It incorporates words and language as a bigger component than other pain scales. It also, collaborates quality of pain with its intensity to give a final score that can be used objectively. [64]

Since the advent of all of these scales, development has focussed much on minor configurations to make them more applicable to the population required to assess. [57]

## Assessing pain in LMICs

Standardised clinical documentation paperwork in Western Cape ECs for all emergency patient clerks, include both a Wong-Baker faces scale, and a NRS. The included scales were agreed through consensus process from local pain experts.

Pain scale reproducibility in emergency centres in LMICs is yet to be determined. Nortje found that experience and expression of pain is culture-determined, when exploring the significance of pain in South African Sotho and Nguni cultures.[65] A single Ethiopian study, which translated the *Brief Pain Inventory* to the Amharic language has proved validity in cancer patients with chronic pain.[66] More research needs to be done to explore the validity of pain scales or modifications to pain scales in LMICs, considering cultural variability.

A small descriptive study conducted at Kenyan surgical ward, aimed at identifying the need for a culturally specific pain assessment tool found that the differences in pain expression between African and Western culture was great. In the former, stoicism was popular; pain was understood to represent weakness; pain was viewed as good and required for recovery; pain seen as punishment.[67]

## Patient Narratives

The McGill pain questionnaire was pivotal in incorporating language into the study of the expression of pain.[64] Its value is that it offers a multidimensional view on pain expression. However, this tool is reliant on single-word adjectives without context.[64]

Patient narratives are commonly used in pain research, as pain scales are usually one-dimensional and often not validated as measures of quality, intensity and perception of pain.[68,69] Patient narratives have the advantage of giving more depth to the description of pain on an individual level as well as allowing for a sense of the cultural expectations and ideology around pain; as well as local language practices in describing pain.[68–70]

Aldrich explored non-acute pain using patient narratives.[57] She found large amounts of variety in patient pain accounts. However, she also found that there was common theme of pain signifying a greater meaning. Similarly, Soderberg and Norberg, used qualitative means to study the language of expression of pain in fibromyalgia patients.[71] They found that the metaphors were a common way to express pain through language. Both these studies found that patient narratives were advantageous as it is not influenced by predetermined categories. This allowed a more accurate reflection of their lived experience. The disadvantage however, is that comparison is difficult, due to differences in language proficiency and use amongst participants.

Wilson, thorough a systematic review of the role of attention on pain descriptors, found that the unique nature of persistent pain is not adequately expressed through pain questionnaires or pain scales.[72] She concluded that personalised narratives may be more valuable to describe the pain experience. More interestingly however, she suggested that language used in

narratives about pain between patients and caregivers may provide a useful adjunct in appropriate pain management. The value of this is still yet to be explored though.

Munday used patient narratives to explore the language used to communicate chronic pain.[73] She concluded that the pain experience is multifaceted, and impossible to adequately understand using single word adjectives. She further found that metaphorical use of language was common across various themes and it may be used as tool to enable understanding.

No studies on the use of patient narratives to explore acute pain are available. Similarly, there is a lack of patient narrative studies with regards to patient pain coming from LMICs.

## Tube thoracostomies

Penetrating chest trauma is a common presentation to South African ECs[74–76], and often requires tube thoracostomy for management of haemothoraces and pneumothoraces.

Thoracostomy tube insertion is understood to be a painful, distressing and anxiety provoking procedure, and most practitioners are taught a similar procedural technique in South African medical education modelled on the Advanced Trauma Life Support (ATLS) course[77]. Traditionally standardised teaching focusses attention the surgical skill of inserting and securing the chest tube, however a protocolised method of analgesia or sedation is not usually available.

Luketich in 1998, found that pain levels during chest tube insertion was excessively high in a group of patients with malignant pleural effusions.[78] In this small study, 12 of 26 patients complained of pain at a level of 9 or more out of 10, with a mean pain score of 6.2, until a protocolised based intervention-group, including specifics regarding local anaesthetics and pre-medication was trialled. In this second group, only 2 of 26 scored 9 or more out of 10, while the mean pain score was 3.7.[78]

There is, however, a paucity of research, both locally and in other LMICs, that explores experiences and expression of thoracostomy-related pain in ECs.

## Conclusion

Oligoanalgesia in the EC is rife, and its causes multifactorial.[1,2,3] Physician-, setting- and patient factors have been shown to play a role in inappropriate analgesia practices in the EC[23,39]. Importantly though, physicians are failing to meet patient expectations regarding analgesia in the EC. [23,39] Research on appropriate access to analgesia in ECs in LMICs is limited by a lack of locally validated, pain scales. The use of pain scales to record pain levels improves pain management.[60] According to international human right law, and supported by

the World Health Organisation, pain management is seen as a fundamental human right.[9] Thus, optimal pain management during the painful procedure may lead to increased patient satisfaction, decreased hospital length of stay or decreased complications.

Pain scales are often translated to different languages. However, in its translation meaning is often lost or misinterpreted, compromising its validity.[70] Further, despite successful translation of pain scales into different languages, differing cultures and dialects mean that these tools often inappropriately categorise pain.[70]

Patient narratives are commonly used in pain research, as pain scales are one-dimensional and often not validated as measures of quality, intensity and perception of pain.[68,69] Patient narratives have the advantage of giving more depth to the description of pain on an individual level as well as allowing for a sense of the cultural expectations and ideology around pain; as well as local language practices in describing pain.[68–70]

Understanding patient expression of pain in a South African EC has not yet been explored. Fully understanding the patient pain experience is paramount to improving analgesia practise and bettering patient outcomes.

## Identification of gaps in the literature, or needs for further research

Whilst there is a vast amount of literature available regarding oligoanalgesia and pain assessments internationally, most of it originates from high income settings. Extrapolation of this information to LMICs, like South Africa, is not always possible due to significant cultural differences. More research originating from LMICs regarding the prevalence of oligoanalgesia and the validity of currently used pain assessment tools is needed.

Currently used pain scales tend to monitor trends in pain, and responses to analgesia, yet are not as valuable in assessing the severity and quality of pain. In the LMIC setting, no tools currently used to assess pain, have been validated for its use in this specific setting.

While some research is available regarding patient narratives as a tool to understand chronic pain is available, there is a paucity of literature surrounding patient narratives as a tool to express acute pain. Similarly, very little of the research on patient narratives and pain originates from low- and middle-income settings.

Further research is needed to explore locally suitable pain assessment tools that are reliable in reproducible. Development of this tool will require a large-scale multi-site exploration of how pain is expressed and communicated. Development of this tool may require a Delphi-type study involving experts in the field.

The more information that can be gathered regarding patient pain experience, the better physicians will be equipped to manage pain, and prevent its complications.

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# Part B: Manuscript in article format

# A qualitative exploration of the language and expression of pain in a Cape Town Emergency Centre

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## Abstract

### Background

*Oligoanalgesia* is increasingly being identified as an issue affecting emergency centres universally, especially in low- and middle-income countries where a lack of culturally specific pain scales compound the issue. Despite successful translation of pain scales into different languages, differing cultures and dialects often lead to the pain experience being inappropriately categorised and communicated. This study aimed to explore the language and the expression of pain in adult patients who required tube thoracostomies for penetrating chest trauma, at a district level hospital.

### Methods

The study was conducted at a district level hospital in Cape Town. An explorative qualitative study design was used, using a single stage semi-structured English language interview. All adults who had a thoracostomy tube inserted for penetrating chest trauma were eligible for inclusion. Audio recordings were transcribed, and thematic content analysis of interview data was performed. 22 participants were interviewed (All male, ages 18-45). All participants could speak English at least as a second language.

### Results

Participants had difficulty expressing pain using language and often used non-verbal means; expressing a limitation of functioning and a need for additional analgesia were common mechanisms to express severity of pain; expression of intensity pain was often conveyed by categorising pain as tolerable or intolerable with the latter associated with hopelessness and defeat. The actual language used was simple, and commonly used colloquialisms unique to the setting. Barriers to communication between patient and doctor related to use and interpretation of pain scales and the poor relationship between doctor and patient.

### Conclusion

This study emphasises the inadequacy of currently accepted pain assessment methods in this setting in terms of use and interpretation. It highlights the need for culturally appropriate tools and training of doctors in communication related to pain.

## Introduction

Oligoanalgesia - the failure to recognise or treat pain - in the Emergency Centre(EC) is rife, and its causes multifactorial.[1,2,3] Physician-, setting- and patient factors have been shown to play a role in inappropriate analgesia practices in the EC[4,5]. Importantly though, physicians are failing to meet patient expectations regarding analgesia in the EC. [4,5]

It is estimated that over half of EC patients have clinically significant pain, and a large proportion of them listed pain as their primary complaint[1,3]. The use of pain scales to record pain levels improves pain management.[6] ECs globally are faced with challenges that may lead to oligoanalgesia. An American study found that 74% of emergency centre patients were discharged with significant levels of pain. [2] ECs in LMICs have a unique set of challenges which may compound the issue of oligoanalgesia in the EC in this setting.[2] Research on appropriate access to analgesia in ECs in low- and middle-income countries (LMICs) is limited by a lack of locally validated pain scales.

According to international human right law, and supported by the World Health Organisation, pain management is seen as a fundamental human right.[7] Thus, optimal pain management during a painful procedure may lead to increased patient satisfaction, decreased hospital length of stay and decreased complications.[8]

Pain scales are often translated to different languages. However, in its translation meaning is often lost or misinterpreted, compromising its validity.[10] Further, despite successful translation of pain scales into different languages, differing cultures and dialects mean that these tools often inappropriately categorise pain.[10]

Patient narratives are commonly used in pain research, as pain scales are one-dimensional and often not validated as measures of quality, intensity and perception of pain.[9,10] Patient narratives have the advantage of giving more depth to the description of pain on an individual level as well as allowing for a sense of the cultural expectations and ideology around pain; as well as local language practices in describing pain.[9–11] The pain experience is understood to be multidimensional, and it has been proposed that biological, psychological and social aspects contribute to the experience and expression of pain.[12,13]

This study aimed to explore the language and the expression of pain in adult patients who received tube thoracostomies at a Cape Town EC.

## Methodology

### Study design

An qualitative approach using an explorative descriptive study design was used.

### Study setting

The study took place at Mitchell's Plain Hospital- a district level hospital in Cape Town. Mitchell's Plain is a low- to middle-income community that struggles with social challenges, including gangsterism, crime, drug abuse, unemployment and poverty[14], and houses a population of approximately 546 000 residents.[15] Approximately 47% of the population speak English as a first language, with an equal percentage speaking Afrikaans primarily.[15] The hospital also services a large nearby area, Philippi and this population speak predominantly isiXhosa as a first language.

Interpersonal violence and other injuries are prevalent and contributes significantly to the burden at Mitchells Plain Emergency Centre. Those with penetrating chest trauma often require a tube thoracostomy. Approximately 60 are performed per month and they spend an average of five days in a thoracostomy suite. The thoracostomy suite is a 'low care' nursing ward where stable patients are nursed in comfortable chairs and mobilisation is encouraged.

### Sampling

#### *Selection criteria*

All adult patients (18 years or older) nursed in the thoracostomy suite, who received a tube thoracostomy were eligible for inclusion. Those who were admitted for longer than a week, patients with impaired or no memory of the tube thoracostomy procedure, patients with cognitive impairment that affected their ability to communicate or provide informed consent and patients who could not speak English fluently were excluded.

#### *Data collection plan*

Interviews took place within 72 hours of the insertion of the tube thoracostomy- evidence suggests that patients remember and recall painful experiences up to one week after the incident.[16]

#### *Sampling strategy*

Purposive sampling was used to ensure a representative mix of patients with a wide variety of backgrounds, ages and English usage.

### Data collection plan

The primary investigator conducted one-on-one semi-structured interviews with each of the participants in a private area outside the thoracostomy suite. Participation was voluntary and participants were interviewed consecutively until redundancy was achieved over a 6-week period between May and June 2019. Patients who met inclusion criteria were approached and consented. The male investigator was dressed and introduced so as to not represent a position of power, and the interviewee were the only people present at the time of the interview. Interviews were conducted exclusively in English – the language of medical practice and documentation.

### Data collection tool

The interview consisted of open-ended questions with pre-configured prompts (see addendum 9). These questions aimed to explore the participants' experience and perception of pain, as well as the words, and phrases they use to express their experience. The questions are derived from previous studies with similar methodologies and themes but were amended to accommodate the specific clinical context.[17]

### Data collection process

The investigator was trained in qualitative research methods and the co-investigators were proficient in qualitative research methodology.

The interview process followed Kvale's "Seven stages of an interview investigation"[18]. Prior to each interview, basic demographic details of each participant were collected. Each interview was recorded on a departmental recording device. No field notes were made during the interviews – answers were however echoed at the end of interview sections, to clarify or confirm statements when necessary. Initial transcription of the anonymised interviews was done independently, where after, the investigators scrutinised the anonymised transcriptions to ensure accuracy of the text. The transcripts were not returned to the participants for review.

### Data management

Transcribed data from the interviews were analysed using thematic content analysis, and the process followed the guidelines of Marshall and Rossman[19]: Coding of the transcribed data was done using both NVivo software [20] as well as manual coding by the research team. Transcribed interviews were analysed for emerging themes, initially individually, and iterative cycles of inductive analysis informed a set of themes. A meeting involving all the researchers was held, where each researcher presented their individually ascertained themes. These were collectively discussed, and common themes were sought. The themes were constructed based on a combination of weight and frequency of language used and verbal expressions

from the transcribed texts. Thick descriptions of participants' experiences and expression of pain were sought to exemplify the data. Specific attention was given to the language used to describe the presence and severity of pain; as well as the analogies, similes and colloquialisms used in this context relating to pain.

Trustworthiness of this study was preserved through transparent and trustworthy study methodology. This is addressed below:

- Credibility of the interviews was ensured through member checking[21]. At the end of each interview, words or phrases that were unclear, or not fully understood were reviewed with the participant for meaning and clarity. Further, after the transcription process, all transcripts were reviewed by the investigators to clarify words or phrases that remained unclear. There was no post-analysis discussion or feedback provided to the participants.
- Tranfererability was ensured by providing adequate circumstantial information regarding the seting, population and data collection process. This, coupled with detailed descriptions of findings will allow readers to extrapolate the findings to their settings.
- The researchers guaranteed dependability by ensuring that the research process and reporting was rational, clear and reflected upon. This ensures that the research is reproducible.
- Conformability was established through all of credibility, transferability and dependability being achieved. The research is thus auditable.

## Ethical considerations

Participation was voluntary and interviews recordings and transcriptions were anonymised. Verbal and written consent was obtained from each participant prior to commencing the interviews. Ethical approval was granted by the University of Stellenbosch's Health Research Ethics Committee (HREC S18/10/205) and facility approval was facilitated via the National Health Research Database website (WC_201904_002).

# Results

## Sample size and demographics

Redundancy occurred after 22 participant interviews. Whilst only four of the participants spoke English as a first language, all could speak English fluently. The age range of participants was from 18 to 45 years (mean=29). Sixty percent of the participants completed at least a Grade 10 level at school, and 14 percent had completed high school (mean=grade 10). Demographic data of included participants are presented in table 1 below.

This study did not explore the relationships between age or level of education and pain expression.

## Interview duration

Interviews ranged from 3 minutes and 33 seconds to 11 minutes and 28 seconds, with a mean interview duration of 5 minutes 42 seconds. No patients refused to participate.

*Table 1*

| ***Participant First Language*** | | **English** | **Afrikaans** | **isiXhosa** | **Other** | **Total** |
|---|---|---|---|---|---|---|
| *Age* | 21 or younger | 0 | 1 | 4 | 0 | 5 |
| | 22-29 | 1 | 2 | 4 | 0 | 7 |
| | 30 or older | 3 | 1 | 4 | 2 | 10 |
| *Highest Level of Education* | Less than Grade 10 | 2 | 2 | 3 | 2 | 9 |
| | Grade 10 or higher | 2 | 2 | 9 | 0 | 13 |
| *Total* | | **4** | **4** | **12** | **2** | **22** |

Themes could broadly be categorised in two: the actual language used to express pain, and the barriers that prevented the expression of pain.

## Language used to express pain

1) The inability to articulate

Many participants found it difficult to adequately communicate their pain when asked. Some mentioned that they had *'no words'*, while others stated that they found it difficult to describe their pain.

> Interviewer: Can you tell me about the pain you experienced?'
>
> *(P10) 'I don't have the words. I understand (what you're asking). I don't know what to say.'; (P11) 'It's indescribable.'; 'sometimes, you don't know the words to use, you know.' (P12) 'Oh, ja, it's very, very difficult for me to explain the pain.'; (P15) 'I'm lost for words, man.'; (P4) 'I would say, I don't know. I don't have a word that comes to mind.'*

2) Limitation of functioning as description of pain

Participants often expressed a decrease in level of functioning or a difficulty in performing normal activities comfortably, as markers of poorly managed pain.

> *(P12) 'When I'm standing up, I suffer. When I'm like sitting, the pain, yoh!... And when I'm sleeping, oh! Yoh! When I'm sleeping, yoh!'; (P16) … 'I couldn't sit.'; (P18) 'I can do nothing, fast.. I can't walk fast, because then I experience my lungs, the pain, and the stabbing on my back.'; 'I can't describe it, because is very sore, because you have to sit very slowly, and get in the right position to fall asleep.'; 'I can't take my jacket off too fast, when I went for the X-ray, because it was painful man.'; (P19) 'I feel some pain, especially (when) I'm coughing, when I'm moving, it's getting worse inside.'; (P20) '…because I told them that I can't breathe properly, ja. And I can't like cough.'; (P22) 'You can't breathe. You can't cough. You can't do nothing with your inside man.'; (P6) 'So I couldn't do anything, I'm just stuck in one place.'; 'I cannot take a bath, because I can't lift my arms.'*

Likewise, return of function was used to express a non-significant or manageable amount of pain.

> *(P19) 'If I'm one out of ten, then I think I can run around, and I tell myself I don't need this (analgesia).'*

3) Need for analgesia as an indicator for significant pain

Pain was often expressed as a need for analgesia, rather than a description of pain:

> Interviewer: 'Okay. And if it was only a five out of ten, what word would you use to describe that one, to the doctor?'
>
> *(P5) 'I will probably ask for medication.'; (P19) 'I suppose, I would tell him all the time, he must get me some painkillers.'; (P12) 'I asked the doctor to give me pills for the pain.'*

4) Hopelessness, defeat and inability to tolerate pain

When expressing their pain, participants frequently used negative thoughts associated with hopelessness and powerlessness, often associated with the connotation of defeat or failure. This association was powerful, in that their pain level was often described on a spectrum from tolerable to intolerable. A morbid theme of death was also present at times.

> Interviewer: 'How bad was the pain?'

*(P15) 'Unbearable… Completely unbearable'; (P11) 'Yoh, I nearly blacked out.'; (P17) 'I was so powerless man'; 'And I'm losing power'; (P5) 'Yoh, I would say that's the worst pain. I can't take it anymore.'; (P6) 'It was quite bad, it was really bad, I couldn't bear it, I couldn't take it.'*

Interviewer: 'Okay. Do you have any words to describe that pain? If we didn't have the scale, do you have any words to describe how bad that pain was, if you just had to tell someone?'

*(P8) 'It felt like death…I was dying'*

Interviewer: 'Okay. What words would you use to describe that pain?'

*(P13) 'The words I would just say is, be prepared to die.'*

Interviewer: 'And if you had a (pain of) ten out of ten, what would you tell the doctor?'

*(P3) 'Bury me.'*

5) Language used to describe pain

Participants regularly made use of interjections, often as part of sentences but also entirely on its own at times. The exclamation, *'yoh'* was most frequently used, across cultural, level of education and age groups. This interjection was often used alone as a response, and at other times as part of an explanation. *'Yoh'* is understood as a South African slang term exclaiming surprise.[22]

Interviewer: 'How strong was the pain, when they put the tube in?'

*(P2) 'Yoh!'; (P3) 'Yoh! Man! Yoh, it was sore, heavy.'; (P5) 'Yoh, this one is quite intense, very intense.'; (P7) 'Yoh, it was a lot of pain.'; (P15) 'Sjoe! Yoh! How do I start? It's very painful, man.'*

Participants defaulted to describing pain as a character as opposed to a level of intensity when asked about their pain. The expression of pain in terms of intensity had to be prompted for specifically.

*(P12) '(it was a) deep pain.'; (P13) 'It's like a sharp stabbing pain.'; (P5) 'I could say it's sharp, it's like something stabbing me.'; 'It was like pricking me.'*

Analogies, metaphors and similes were sometimes used. These were most prevalent amongst the first language English speaking participants.

*(P13) '(it's like) someone take a steel boot and kicks you.'; I'd say, someone has kicked a ball straight at you, and you could have caught it, but you didn't listen. Instead you*

*turned away and the ball hit you against the head.'; (P 21) 'I would say it's something like giving birth.'*

Despite all participants being multilingual, codeswitching (moving between two languages or styles) was limited to expressions of pain, although colloquialisms were common . We noted that the interviews were conducted in English, participants were not always first language English speakers, and one might expect levels of anguish to best expressed in a native language.

*(P17) 'Actually, at times I feel eina.' Δ; (P2) 'Baie strong, because the pipe is too sore, ja, I have got lot of pain.'; 'ek het baie pain; that is the one problem, that I feel baie pain.' °*

*(Δ eina – Afrikaans word for ouch/sore) (° baie – Afrikaans word for "a lot of")*

Participants frequently made use of adverbs such a 'very', 'really', 'so' or 'too', often repetitively and consecutively to emphasise intensity.

*(P19) 'It was very very painful'; (P12) 'Let's see, I can say, the pain… it's very sore. It is very bad. It's very painful. Very painful. Very, very bad, you know, and it's very painful.'; (P4) 'Mm, was strong, too much strong.'; (P9) 'It was so strong.'; (P6) 'It was really, really painful.'*

In terms of the actual specific words used, the words that were prompted by the questions asked (i.e. 'bad' or 'strong') were most often used. Usually, preceded by an adverb to quantify the intensity.

Interviewer: 'And how strong was the pain?'

*(P4) 'Not so strong.'*

Interviewer: 'How bad was the pain?'

*(P9) 'It was so bad.'*

Compared to a validated pain intensity scoring system that is based on vocabulary, namely, the McGill Pain Questionaire, only a few of the words were used by participants in the study. These were: 'stabbing' (3 participants), 'sharp' (3 participants), 'sore' (15 participants), 'heavy' (2 participants), 'intense' (3 participants), 'unbearable' (2 participants), 'numb' (2 participants).

### 6) Non-verbal communication

A significant portion used non-verbal cues indicating that they were unable to verbalise the severity of their pain. Shaking of heads in silence expressing dissatisfaction and grimaces expressing anguish were common.

Similarly, participants mentioned pain being expressed as an emotive process.

> *(P15) 'You almost feel like crying, and stuff like that.'; (P12) 'I would say, I was crying a lot, because I felt pain.'; (P16) 'Ten out of ten, I'll cry.'; (P17) 'Screaming, like just angry.'; (P18) 'If I have to cry to the doctors, to really make them understand.'; (P22) 'Till by number ten. Like this morning, I did cry.'*

## Barriers to expression of pain

### Pain Scales

While the study aimed to explore the actual language used to express pain, it became evident that barriers to the expression of pain exist. Some of these barriers related to the use of the pain scales themselves.

The Wong Baker Faces Scale and the Numeric Rating Scale (NRS) both exist on the standardised stationery used in Western Cape Department of Health ECs, like Mitchells Plain Hospital. Despite this, the scales were poorly recognised by participants. Almost all the participants were seeing the scale for the first time at the time of the interview.

When the scales were presented to participants, it was noted that while a good inter-scale correlation existed, there was little correlation between the intensity of pain described verbally and that represented on the pain scales, particularly with medium to lower pain intensities.

For example: the same interviewee who responded, *'I didn't feel pain that moment',* when asked about the pain experienced at the time of tube insertion, rated the pain a '*six'* when asked to rate it on the numerical scale. Similarly, a different participant mentioned, '*when the tube was placed, I didn't feel much pain'* but scored the pain at that time as *'seven'* on the numeric scale.

Of note, on the ten-point NRS more than 50 percent of participants chose either the numbers six or ten to describe their pain.

It is noted that higher pain scores were generally appropriately described.

> Interviewer: 'How would you describe a ten out of ten pain?'
>
> *(P21) 'Excruciating.'; (P6) 'I would just say it's really terrible.'; (P7) 'I think it's worst.';*
>
> *(P15) 'It's too much pain.'*

There was a lack of variability in the language used to differentiate middle and lower scores.

> Interviewer: 'How would you describe a five out of ten pain?'

*(P16) 'I don't know, it's just a little.'; (P17) 'Ja, like at least I can manage.'; (P20) 'it's getting better now.'; (P21) 'I'd say… not bad.'; P7: 'I don't get pain.'*

Interviewer: 'How would you describe a one out of ten pain?'

*(P11) 'Ja, it's okay.'; (P14) 'It's alright.'; (P15) 'That's not bad.'; (P18) 'I would put that as a minor pain, not a severe pain.'; (P6) 'If it was on one, I would say it was fair.'*

### Doctor- Patient Relationship

Frequently, participants alluded to a power gradient existing between themselves and the doctors managing their pain when asked about their ability to describe their pain to their doctor.

*(P12) 'I didn't want the doctors to have little mercy on you, and they're putting their tubes, and how they put in their tubes. I must not tell them how they must put in their tubes, I can't know anything.'; (P15) 'No, you can't complain. You (are) a patient.'; (P4) 'I'm scared of them (the doctors).'*

Some participants normalised their pain experience as an acceptable part of the healing process, with elements of guilt and self-blame contributing to this.

*(P13) '...the pain was actually more my cause than theirs.'*

Interviewer: 'Did you complain about the pain?

*(P1) 'No. because I'm a patient, I want to be healthy.'; (P12) 'I didn't want the doctors to have little mercy on you.'*

Similarly, the population made up of young male participants, expressed a degree of stoicism when it came to pain, and their expression thereof towards those deemed to be helping them.

*(P9) 'I don't cry.'; (P2) 'I'm trying not to complain.'; ( P12) 'I must not tell them how to put in their tubes.'*

Further, there was a vast disconnect between the patient's pain experience, and what they believed the doctor comprehended.

Interviewer: 'We heard from some patients that they find it difficult to describe their pain to the doctor. Do you think that the doctor or the nurse who was involved, understood that you were in pain?'

*(P4) 'I don't think so…Because she can't feel the pain like me.'*

Interviewer: 'Do you think the doctor understood how bad your pain was?'

*(P11) 'Not really, not really.'; (P20) 'I don't think they understand how bad it is, they just understand that I'm in pain.'*

Interviewer: 'Do you think the doctor understood that you were in pain?'

*(P8) 'No, because he didn't change anything; he didn't understand.'*

## Dimensions of pain expression

The results of the study were consistent and could be matched with 6 key dimensions of pain as depicted in figure 1 below, based on 'the dimensions of pain' by Petty and Moore.[13]

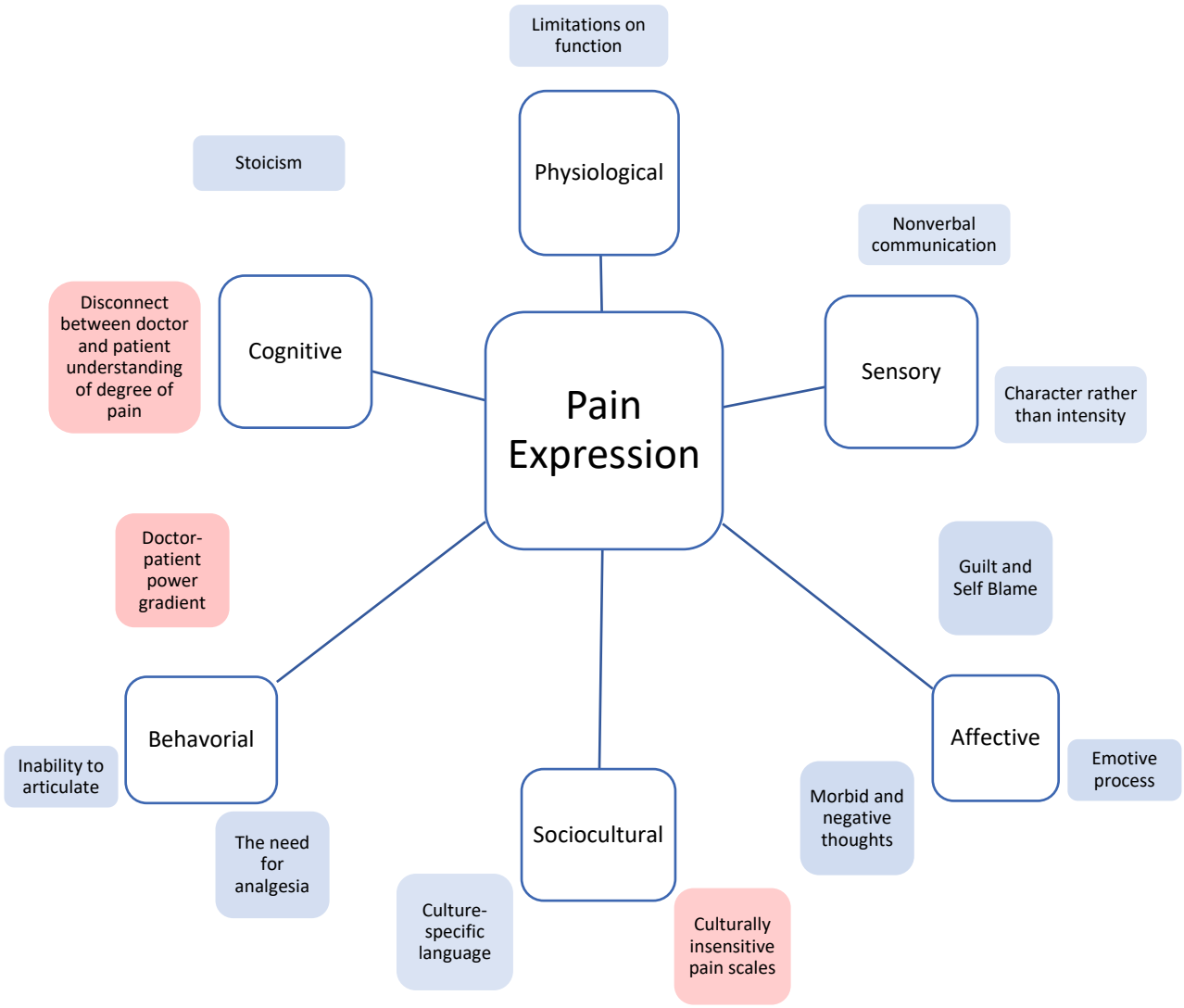


*Figure 2: Conceptual framework of themes arising from coding process related to the dimensions of pain. Red blocks relate to barriers to communication. Blue blocks relate to the actual language used.*

# Discussion

Providing appropriate pain management is reliant on adequately recognising, assessing and treating pain. This small study demonstrates numerous barriers particularly to the recognition and assessment of a pain in a Cape Town emergency centre - thus leading to its ineffective management and oligoanalgesia. Understanding how patients express their pain could be pivotal in improving patient care.

Pain is understood physiologically to warn of tissue injury.[25] Pain thus serves to prevent one from exacerbating injuries through physical actions. This was reflected through participants frequently using descriptions of limited functioning as a verbal representation of their pain.

Oligoanalgesia was highlighted in this particular clinical context. Participants frequently alluded to not receiving enough analgesia to control their pain. They often used sentences or phrases expressing the desire for more adequate pain control as an indicator of pain severity. This may be related to the particular clinical condition and traditional management of these patients – as these are usually healthy young men considered low risk, stable patients in an emergency environment, they are not prioritised in terms of care and have limited physician engagement. The frequency of chest trauma in this setting and the nature of the injury with the associations with interpersonal violence and gangsterism, may also contribute to the lack of significance placed on analgesia adequacy.

While this population tended to struggle with using formalised pain scales to demonstrate their pain intensity, they frequently used a verbalised spectrum of pain from that which is tolerable, to refer to mild or no pain, to the intolerable, which referred to more severe pain. This intolerability extended to morbid themes of defeat, hopelessness and giving up in the face of significant pain. This was similar theme to Munday's research, finding 'pain as overwhelming'.[26]

In terms of the actual words used, this population's language differed in many ways from previous similar studies done in other settings. Language use was simple, and often reliant on the probing questions to provide the vocabulary to express degrees of intensity. While metaphor and analogies played a role in descriptions of pain, these were most evident in those that spoke English as home language. Colloquial terminology was used frequently, and it was expected by participants that the interviewer was able to understand the intensities expressed by them. Seven of the words used on the McGill pain questionnaire, an accepted pain scoring system using verbal descriptors, were mentioned by participants – most of these related to pain quality.

Understanding pain is complex. Untreated pain can have negative short and long term sequelae.[27] Currently, the NRS and Wong Baker Faces Scale are available to doctors at every EC patient encounter to document the level of pain. However, these are appear to be seldom utilised. It must be noted that the neither of the scales showed value in this population. Severe pain correlated well with high scores on the rating systems, but mild and moderate pain were described similarly. Only 2 numbers on the NRS were used frequently. The lack of variability of language used to describe mild or moderate pain, may lead us to consider a more abbreviated pain scoring system in this population.

Culture, language and level of education are all factors that influence the expression of pain, and this was highlighted by the population of this study.[23] Globally used pain scales are not entirely understood by this population, and thus may inadequately categorise pain in terms of severity.

In this setting, pain was expressed both verbally and non-verbally. While some participants were comfortable expressing pain using language, for others, physical expressions of emotions, such as crying or screaming, was the natural response to severe pain. Some participants expressed their inability to articulate their pain. Understanding pain severity through observing facial expressions and emotions may be more useful in this population. [24]

Patient-centred care is increasingly being recognised to improve the quality of care provided to patients.[28] A power gradient existing between doctors and patients may negatively impact the communication between patient and doctor.[29] This study echoed this sentiment, as participants often endured severe pain in silence as a result of a power differential between them, and those they were expected to report pain to.

This silence in the face of pain was not always due to the relationship between the patient and the doctor, but often due internal patient factors. Sentiments of guilt and self-blame were rife. This often lead to thoughts that pain was normal, and needed to be tolerated as part of the greater healing process. Similarly, complaining of pain was seen to show a lack of courage or machismo, in a population exclusively made up of young males.

It was evident that patients did not feel that doctors understood their degree of pain. This detachment between a patient's experience, and a doctors understanding may compound the issue of oligoanalgesia. It was noted that indirect methods of pain expression were common in this population where use pain scales, or direct probing about pain experience was rare.

When matched to a framework of dimensions of pain, pain expression in this population could be categorised accordingly. It is clear that in this population, the biopsychosocial model of pain applies to its expression. It must be noted however, that the sociocultural dimension, followed by the physiological dimension were the most frequent themes found in this population.

## Limitations

Several limitations are acknowledged. This study asssesed a single emergency centre with a narrow socio-cultural demographic. The population, while reflective of the clinical population receiving chest tubes, did not reflect the demographics of South Africa or even the Western Cape. However, the study aimed to serve as a pilot to understand pain expression in a stable EC population in a clinical condition that is generally homogenous and reproducible in terms of procedures and management.

The study was conducted exclusively in English and excluded participants who were not fluent in English. Most pain assessment tools are in English and the aim was to assess their validity in this population. A second part of the study is planned, where Afrikaans will be used as the medium of the interviews.

Redundancy was achieved after 22 participants. It is unclear whether enrolling further participants would have identified further themes.

Interviews were largely very brief. It is unclear whether the reason for this was that participants were unsure of the value of the interview, were unable to express themselves or felt uncomfortable being interviewed while still being a patient and under care at the hospital.

Future research should consider the limitations mentioned and evaluate a broader sample at mulitiple sites and include various pathologies. It should also explore factors that may contribute to a generalisable evidence based pain assessment tool for emergency centres.

## Conclusion

Pain assessment is an invaluable tool in patient care, yet current methods are failing to adequately assess and thus appropriately manage patient pain. The currently available pain assessment tools are seldom used and generally not well understood. Qualitative expressions of pain may be more valuable than the quantitative expression represented by pain scales. Further research into culturally appropriate measures of pain and training for providers on communication around pain are needed.

## Competing interests and funding

This study was self-funded by the researchers. There are no conflicts of interests to declare.

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# Addendum 1: List of themes from analysis of data

- Language used to express pain
    - The inability to articulate
    - Limitation of functioning as description of pain
    - Need for analgesia as indicator of significant pain
    - Hopelessness, defeat and inability to tolerate pain
    - Actual language used
        - Frequent interjections including colloquialisms
        - Character as opposed to intensity
        - Analogies, metaphors and similes
        - Codeswitching
        - Repetitive use of adverbs and adjectives for emphasis
        - Use of prompted words
    - Non verbal communication
        - Emotions expressed
        - Facial expressions
        - Silence
- Barriers to communication
    - Pain scales
        - Infrequently used
        - Poorly understood
        - Infrequent use of most numbers
        - Lower and middle pain score described simarlarly
    - Doctor-patient relationship
        - Power gradient
        - Self blame and guilt
        - Stoicism
        - Doctor not understanding degree of pain

# Part C: Addenda

## Addendum 1- Author information pack (AFJEM)

Available:

https://www.elsevier.com/wps/find/journaldescription.cws_home/725742?generatepdf=true

# Addendum 2- COREQ checklist

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 30 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 27 |
| Occupation | 3 | What was their occupation at the time of the study? | 27 |
| Gender | 4 | Was the researcher male or female? | 30 |
| Experience and training | 5 | What experience or training did the researcher have? | 30 |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 30 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 31 |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 31 |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 31 |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 30 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 30 |
| Sample size | 12 | How many participants were in the study? | 32 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | 32 |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 30 |
| Presence of nonparticipants | 15 | Was anyone else present besides the participants and researchers? | 31 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 30; 32 |
| *Data collection* | | | |

| | | | |
|---|---|---|---|
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 31 |
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | 30 |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 31 |
| Field notes | 20 | Were field notes made during and/or after the inter view or focus group? | 31 |
| Duration | 21 | What was the duration of the inter views or focus group? | 32 |
| Data saturation | 22 | Was data saturation discussed? | 30; 32 |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or correction? | 31 |
| | | | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | 31 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | 47 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 31 |
| Software | 27 | What software, if applicable, was used to manage the data? | 31 |
| Participant checking | 28 | Did participants provide feedback on the findings? | 31 |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings?<br>Was each quotation identified? e.g. participant number | 33-40 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 39 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 40; 47 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 33-40 |

**Addendum 3- Proposal**

Dissertation Proposal

# A qualitative exploration of the language and expression of pain in a Cape Town Emergency Centre

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This study is in partial fulfilment of the Master of Medicine (Emergency Medicine) degree

## Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Muhammad Shaheen Kajee

10 March 2019

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8. I know that plagiarism is a serious form of academic dishonesty.
9. I have read the document about avoiding plagiarism, am familiar with its contents and have avoided all forms of plagiarism mentioned there.
10. Where I have used the words of others, I have indicated this by the use of quotation marks.
11. I have referenced all quotations and properly acknowledged other ideas borrowed from others.
12. I have not and shall not allow others to plagiarise my work.
13. I declare that this is my own work.
14. I am attaching the summary of the Turnitin match overview

Muhammad Shaheen Kajee

10 March 2019

# List of Tables

# Abstract

## Introduction

Pain affects the majority of patients presenting to emergency centres (ECs). *Oligoanalgesia* is increasingly being identified as an issue affecting emergency centres universally. In low- and middle-income countries, a lack of culturally specific pain scales compound the issue, as physicians are failing to meet patients' expectations with regards to analgesic requirements. Despite successful translation of pain scales into different languages, differing cultures and dialects often lead to the pain experience being inappropriately categorised and communicated.

### Aim

To explore the language and the expression of pain in adult patients who required tube thoracostomies for penetrating chest trauma, at a district level hospital.

## Methodology

The study will take place at Mitchell's Plain Hospital - a district level hospital in Cape Town, South Africa. An explorative qualitative study design will be used, using a single stage structured interview. The interview will consist out of open-ended questions that will be asked to all participants. All adults who had a thoracostomy tube inserted for penetrating chest trauma will be eligible for inclusion. Audio recordings will be transcribed and data from the interviews will be analysed using thematic content analysis. Transcribed interviews will be analysed for emerging themes, both individually and as a group, and iterative cycles of inductive analysis will inform a set of themes. Specific attention will be given to the language used to describe the presence and severity of pain; as well as the analogies, similes and colloquialisms used in this context relating to pain.

## Ethical Considerations

Participation in this study is completely voluntary and informed consent will be obtained prior to the initiation of surveys. No identifying information will be collected, and the interviews will not interfere with the clinical care. No information regarding the treating clinicians will be collected and therefore this study poses no risk to any clinician. Ethics approval will be obtained from Stellenbosch University Health Ethics Research Committee (HREC).

## Discussion

Findings will be used to increase our knowledge base regarding patient experience and expression of pain in emergency centres. Information from this study could be used in the

development of a pain assessment scale applicable to the South African setting. Information from this study could be used to develop a pain assessment scale applicable to the South African setting.

## Background

Pain affects the majority of patients presenting to emergency centres (ECs).[1,2,3] Johnston, in 1998, estimated over 50% of patients, both adults and children, complained of clinically significant pain on EC admission.[1] Similarly, in 2003, Cordell found a high prevalence of pain at presentation in an American EC, with over 61% of patients having pain. It was further noted that pain was the primary complaint in 52% of the presentations.[3] The Pain and Emergency Medicine Initiative (PEMI) multicentre study across North American ECs, noted that pain intensity at presentation was severe (median 8/10).[2] They further noted that while initial pain assessments were common, re-evaluation of pain was uncommon. Only 60% of these patients in pain received analgesia and usually after a lengthy wait. They concluded that EC pain is common, its intensity severe, analgesia under-used and delays to analgesia rife.[2] A study conducted at a Cape Town paediatric trauma unit found that while pain and anxiety scores were generally low, only two-thirds of patients were offered analgesia- and less than 60% of those had moderate to severe pain.[4]

Optimal pain management is noted to increase patient satisfaction, doctor patient relationship and decrease patient distress.[5] The World Health Organisation (WHO) has decreed pain management as a human right.[6] Yet, *oligoanalgesia* - failure to recognise or treat pain - in the EC is increasingly being acknowledged.[7,8] Todd's Pan-American EC study found that 74% of patients were eventually discharged with pain scores in the moderate or severe category.[2] Fosnocht has postulated that emergency provider focus has shifted to finding and managing the cause of patient pain as opposed to treating the underlying pain itself, despite pain being the reason for presentation.[9]

A review of available literature demonstrates that oligoanalgesia is usually secondary to some, or combinations of the failure to acknowledge, assess or document pain; failure to assess response to pain treatment; failure to institute analgesia protocols in the EC and failure to meet patient expectations with regards to analgesic requirements.[10,11]

Relationships between demographic factors and oligoanalgesia have also been documented.[10] Todd, in two separate studies, has demonstrated ethnic minorities in an American population receive less analgesia than their white American counterparts.[2,12] Similarly, gender and age bias with regards to analgesic prescription have been shown to exist, with males and nonelderly patients susceptible to suboptimal analgesia practises.[13,14]

Current available literature has also noted physician related factors as barriers to analgesia.[10] This includes insufficient training in pain management received by emergency practitioners[15] and underestimation of patient pain by physician.[16] The concept of physician opiophobia is a

concept that has been receiving much needed attention.[17] The portmanteau of the words opioid and phobia, refers to the irrational fear of opioids. Neighbor demonstrated underuse of opioids for trauma victims[18], while Bijur demonstrated that the widely accepted dose of 0.1mg/kg of morphine to be ineffective in controlling acute severe pain.[19]

The emergency centre itself provided additional challenges to optimal analgesia practises. Hwang has demonstrated a 2-hour delay to analgesia in patients with hip fractures presenting to an EC caused by EC overcrowding (defined as over 120% capacity).[20] Similarly Pines and Hollander concluded that EC crowding resulted in delays or overall omission of pain management in patients with severe pain.[21]

While most research regarding analgesia, or lack thereof, in the EC originates from hospitals in high-income countries (HICs), Olakulehin, through a Nigerian cohort, proposed that a significant discrepancy exists between patient and healthcare provider estimation of pain during painful emergency centre procedures.[22] Healthcare practitioners in Rwanda, had limited acute pain management training, with regards to post-operative surgical pain, and feared side effects of certain drugs.[23] This demonstrates similar barriers to analgesia in HICs and low- and middle-income countries (LMICs). More so, LMICs struggle with EC overcrowding[24] and this further compounds delays and limits the prescribing of analgesia and its administration.

Acknowledging, assessing, documenting and assessing response to treatment of pain are fundamental in preventing oligoanalgesia and decreasing patient suffering.[10] Pain scales are central to this process. Pain scales used to determine patient experience of pain are commonly used in clinical medicine to improve analgesia practices.[25] Commonly, the Visual Analogue Scale (VAS), Verbal Rating Scale (VRS), Numeric Rating Scale (NRS) and the Wong Baker Faces Pain Rating Scale are used to assess pain in all medical departments including post procedural pain and pain the EC[26,27,28,29] While all have shown strong validity in clinical trials mostly in HICs[28], each have varying strengths and limitations. The VAS has infinite response categories, but is time consuming, requires extra steps and is slightly more complex to use for certain populations (e.g. elderly).[28] The VRS is easy to use and score, but requires a vocabulary in the language it is being administered in, and only allows for a limited number of possible responses.[28] The NRS, has many (but not infinite) response categories, is easy to score but ratio data of responses cannot be calculated.[28] The Wong-Baker Faces Pain Rating Scale was initially developed for children due to its simplicity, but its validity has been proven in adult populations subsequently.[29–31]

Pain scale reproducibility in emergency centres in LMICs is yet to be determined. Nortje found that experience and expression of pain is culture-determined, when exploring the significance

of pain in South African Sotho and Nguni cultures.[32] A single Ethiopian study, which translated the *Brief Pain Inventory to Amharic language* has proved validity in cancer patients with chronic pain.[33] More research needs to be done to explore the validity of pain scales or modifications to pain scales in LMICs, considering cultural variability.

Penetrating chest trauma is a common presentation to South African ECs[34–36], and often requires tube thoracostomy for management of haemothoraces and pneumothoraces. Tube thoracostomy is thought to be painful, distressing and anxiety provoking. Luketich in 1998, found that pain levels during chest tube insertion was excessively high in a group of patients with malignant pleural effusions.[37] In this small study, 12 of 26 patients complained of pain at a level of 9 or more out of 10, with a mean pain score of 6.2, until a protocolised based intervention-group, including specifics regarding local anaesthetics and pre-medication was trialled. In this second group, only 2 of 26 scored 9 or more out of 10, while the mean pain score was 3.7.[37] There is however, a paucity of research, both locally and in other LMICs, that explores experiences and expression of pain in ECs.

## Motivation

Oligoanalgesia in the EC is rife, and its causes multifactorial.[1,2,3] Physician-, setting- and patient factors have been shown to play a role in inappropriate analgesia practices in the EC[10,11]. Importantly though, physicians are failing to meet patient expectations regarding analgesia in the EC. [10,11] Research on appropriate access to analgesia in ECs in LMICs is limited by a lack of locally validated, pain scales. The use of pain scales to record pain levels improves pain management.[28] ECs globally are faced with challenges that may lead to oligoanalgesia. ECs in LMICs have a unique set of challenges which may compound the issue of oligoanalgesia in the EC in this setting. According to international human right law, and supported by the World Health Organisation, pain management is seen as a fundamental human right.[6] Thus, optimal pain management during the painful procedure may lead to increased patient satisfaction, decreased hospital length of stay or decreased complications.

Patient narratives are commonly used in pain research, as pain scales are one-dimensional and often not validated as measures of quality, intensity and perception of pain.[38,39] Patient narratives have the advantage of giving more depth to the description of pain on an individual level as well as allowing for a sense of the cultural expectations and ideology around pain; as well as local language practices in describing pain.[38–40]

Pain scales are often translated to different languages. However, in its translation meaning is often lost or misinterpreted, compromising its validity.[40] Further, despite successful translation of pain scales into different languages, differing cultures and dialects mean that these tools often inappropriately categorise pain.[40]

### Aim

To explore the language and the expression of pain in adult patients who received tube thoracostomies for penetrating chest trauma, at a district level hospital.

### Objectives

1. To explore the language and the expression of pain and discomfort during tube thoracostomy insertion.
2. To explore the language and verbal expressions used to rate pain intensity.

## Methodology

### Study Design

An explorative qualitative study design will be used, using a single stage structured interview. This research project will, for practical purposes, be divided into two parts that will run concurrently. Part 1 will explore participants with English as first language and Part 2, participants with Afrikaans as first language.

For the purposes of the MMed dissertation(Kajee), the English data will be analysed and presented in a publication. The Afrikaans data will be included in a second publication (not for degree purposes), analysing and comparing the data of both data sets. We believe that the composite data pool analysis and comparison will be out of the scope of a professional Masters dissertation.

### Study Setting

The study will take place at Mitchell's Plain Hospital - a district level hospital in Cape Town, South Africa. The emergency centre serves 50 000 patients annually, with approximately half being of high acuity (orange or red triage according to the South African Triage Scale).

Mitchell's Plain, on the *Cape Flats* of Cape Town, was developed by the apartheid government in the 1970s as part of the execution of the Group Areas Act, which forcibly removed residents from their homes and reallocated them according to the racial segregation law of the time.[41] Under this act, Mitchell's Plain became a low- to middle-income community for a large part of the *coloured* population of Cape Town. The area struggles with social challenges, including gangsterism, crime, drug abuse, unemployment and poverty[42], and houses a population of approximately 546 000 residents - 91% *coloured* and 7% *african*.[43] Approximately 47% of the population speak English as a first language, with an equal percentage speaking Afrikaans

primarily.[43] The hospital also services a large surrounding area, due to a lack of appropriate facilities in the near vicinity.

The Mitchells Plain EC case mix follows national trends with regards to the quadruple burden of disease: HIV/AIDS and Tuberculosis (TB); maternal and child mortality; violence and injuries; and non-communicable diseases (NCDs). Interpersonal violence and other injuries are particularly prevalent during weekends. The majority of these patients are young men, most of them coloured. The overwhelming proportion of them required a unilateral thoracostomy tube- approximately 60 per month. Most of them are nursed in a tube thoracostomy suite and the average length of stay is 5 days for a simple pneumothorax or for a haemothorax. The tube thoracostomy suite is a 'low care' area where stable patients are nursed in comfortable chairs and mobilisation is encouraged.

An informal audit of all patients in the EC [n=88] revealed that 92% had some degree of pain at any given time; 65% of them had no analgesia prescribed prior to the consultation; 27% had analgesia prescribed and administered prior to being consulted and 8% had analgesia prescribed and not administered. The audit revealed that the median improvement in pain score using the VRS was from 7/10 to 5/10. Very few patients had any follow up to assess improvement of pain after administration of analgesia.

## Study Population and Sampling

All adult patients (>18 years) who had a thoracostomy tube placed for penetrating chest trauma at Mitchells Plain Hospital between April to June 2019 will be eligible for inclusion.

Consecutive patients who meets inclusion criteria will be approached and consented. Interviews will take place preferably within 48 hours of the insertion of the tube thoracostomy, however evidence suggests that patients remember and recall painful experiences up to one week after the incident.[44] Choosing patients who received tube thoracostomies essentially represents a convenience sample – a purposive sampling method to ensure that the sample contains a mix of patients with certain characteristics (young patients with significant pain who were admitted to the hospital for a few days and who are readily accessible). In the event of there being more than the required number of consenting volunteers for the study on a particular day, they will be prioritised in order of time since receiving the thoracostomy tube insertion – the participant with the shortest time since the procedure will then be interviewed first. Please refer to Appendix 1 for a graphica representation of the enrolment process.

Thoracostomy tube insertion is understood to be a painful procedure, and most practitioners are taught a similar procedural technique in South African Medical education modelled on the ATLS course[45], providing a semi standardised reference point. The group of patients represents a convenient sample of not acutely unwell (they are mobile and are largely

independent of specialised nursing for self-care), are admitted and do not usually require time dependant investigations or management otherwise. All patients who meet criteria will be invited to participate during four weekend day visits over 1 month by the primary investigator. An estimate of 10-12 patients for both groups (20-24 patients in total) is expected based on literature suggesting that 10 participants is likely enough to facilitate this research framework.[46] Participation is voluntary, and sampling will continue until redundancy occurs with a minimum of 10 participants.

Exclusion criteria:

1) Patients < 18 years old
2) More than one week after tube thoracostomy has been performed
3) Patients who has no / impaired memory of the procedure (who has received procedural sedation)
4) Patients who cannot speak English nor Afrikaans
5) Patients with cognitive impairment that affect their ability to communicate and/or provide informed consent

## Research Procedures Data Collection Methods

Data collection will occur in two concurrent parts: part 1 for participants with Engilsh as first language and part 2 for those with Afrikaans as first language.

2 trained interviewers – first language English and first language Afrikaans speakers will conduct structured interviews with participants who are able and willing to consent. Both interviewers will be present during the same session and those that consent will be interviewed by the first language speaker alone. The interview will consist out of open-ended questions that will be asked to all participants in the language of their choice. These questions will aim to explore the participants' experience and perception of pain, as well as the words, and phrases they use to express their suffering. The questions are derived from previous studies with similar methodologies and themes but will be amended to accommodate the specific theme.[47] These questions will be piloted before implementation: five patients from each group, with tube thoracostomies will be interviewed briefly to assess the responses. The pilot patients will be taken from the same sample and have same inclusion and exclusion criteria. The questions will also be discussed and edited with two external qualitative researchers and a pain expert to assist with the validation process.

The interviewers will be health care workers but not on duty in the facility or in a position of power, to improve the credibility of the responses. The interviewers will be clothed in such a way to not imitate a health care provider and therefore biasing the answers. The interview will start with a brief introduction and summary of the aims of the research project. A few

demographic details will then be obtained (Appendix 2), as well as important information which will be used to elucidate whether any exclusion criteria exist. This will include the gender, age of the participant; the time and date of the injury, as well as the type of injury sustained; the participants' home language and level of education. The interviews will be conducted in a private setting in the hospital, at a time of convenience to the interviewer and participant. The same semi structured interview will be used for all participants (appendix 4)

Question 1 is aimed to assess the experience and perception of pain when the tube thoracostomy was performed. This will be an open-ended question and ample uninterrupted time will be provided for the participant to answer. An introduction before the onset of the interview will explain to the participant what is expected. The prompt on question 1 is based on McGill's Pain Questionnaire and tries to establish the intensity of the pain without the use of a pain scale[48]. Questions 2-4 explore the language used to describe different intensities of pain. The participant will be presented with two pain scales (NRS and Wong-Baker FACES) and asked to describe each of the extreme data points (1/10 and 10/10 of the NRS and the 'happiest' and 'saddest' on the Wong-Baker Faces scale) The participant will also be asked to provide a rating as per the Wong-Baker faces scale, of their pain at the time of tube thoracostomy. This scale is used for the rating, as the current medical notes in use by Western Cape ECs (including Mitchell's Plain EC) makes use of the scale. Question 5 elicits possible barriers to communication of pain by patient to doctor. It is important to realise that no pain scale has been validated (i) for the use in an emergency centre and (ii) specifically for use in our multi-cultural society. The currently used pain-scales on the formal documentation in all emergency centres has been included based on a consensus process from pain experts.

Audio recordings will be transcribed soon after the interviews have been completed in batches of three. This will allow the interviewer to reflect on the interviews so that areas of improvement can be identified, for example not allowing the participant to finish the sentence.

Kvale's "Seven stages of an interview investigation" will be followed and adhered to.[49] Kvale outlined the following stages of the interview investigation to guide the researcher through the research process:

1) Thematising - clarifying the purpose of the investigation
2) Designing - planning the study to obtain the intended knowledge, and considering moral implications
3) Interviewing - conducting the interview
4) Transcribing - preparing the interview material to be analysed, usually by converting recordings into written text
5) Analysing - using an appropriate method to analyse the data retrieved

6) Verifying - confirming the reliability, validity and generalisability of the findings
7) Reporting - communicating the findings in an ethically sound, readable product

## Data Safety and Monitoring

No patient identifying information will be collected. At the time of interview, notes and recordings will be anonymised to a unique study number to protect each patient's identity. Interview notes, audio recordings and transcriptions from interviews will be stored on a password protected computer in the divisional office and backed up on a password protected cloud service - only principal investigators will have access to these files. The passwords will only be known to the researchers. No personal information of clinicians or patients will be stored. Audio data and notes will be anonymised. Audio data and notes will be deleted after use.

## Data Analysis

Transcribed data from the interviews will be analysed using thematic content analysis, and the process will follow the guidelines of Marshall and Rossman[50]:

1) Recording of data by audio recorder or digital voice recorder

2) Verbatim transcription of responses

3) Thorough read through and studying of entire transcribed text

4) Coding process

(a) Open coding – the identification and naming of segments of meaning from the field notes and transcripts in relation to the research topics.

(b) Axial coding – reviewing and examining the initial codes that were identified during the previous procedure outlined above – Categories and patters are identified during this step and organised in terms of causality, context and coherence.

(c) Selective coding – selective scanning of all codes that were identified for comparison, contrast and linkage to the research topic

5. Evaluating relevance of codes to research aims

6) Listing of codes in categories according to research aims

7) Analysis of codes and categories – discussions regarding the relationship in meaning between categories, what can be deducted from the categories as a whole, what meaning was missing, what was foregrounded in the analysis, etc.

8) Description of the thematic relationships and patters of relevance

Coding of the transcribed data will be done using NVivo software (for Engish data)[51]and manual coding by the research team for English and Afrikaans data. Transcribed interviews will be analysed for emerging themes, both individually and as a group, and iterative cycles of inductive analysis will inform a set of themes. Thick descriptions of participants' experiences and expression of pain will be used to exemplify the data. Specific attention will be given to the language used to describe the presence and severity of pain; as well as the analogies, similes and colloquialisms used in this context relating to pain. These will be described separately. Member checking, if necessary, will be done immediately after an interview through engagement with the participant, to clarify certain statements.

The themes derived from the two data sets (English and Afrikaans) will be compared post-hoc and commonalities explored.

## Ethical and Legal Considerations

### Patient

Participation in this study is completely voluntary and informed consent will be obtained prior to the initiation of surveys (Appendix 2). No patient identifying information will be collected,. Information will be stored on a password protected computer in the divisional office and backed up on a password protected cloud service – only the principal investigators will have access to these files. Emotional support and counselling will be offered to patients experiencing significant anxiety. This will be done by the treating clinician, and their team with assistance from the operational manager at Mitchells Plain Hospital, and an in-house clinical psychologist. In the event that a potential participant is experiencing significant pain at the proposed time of the interview, a clinician or senior nurse will be informed, and the interview will be cancelled or postponed, depending on the circumstances. The interviews will be conducted after the initial emergency care has been completed – therefore not interfering with the clinical management.

### Clinicians

No information regarding the treating clinicians will be collected and therefore this study poses no risk to any clinician. Feedback of study results will be anonymised, and it will be impossible to trace back patient care to treating clinician.

### Hospital

The study results may demonstrate that analgesic practices are not great and that patients experience significant discomfort. This may have a negative impact for the specific hospital with regards to its reputation, including the emergency centre. The hospital name will, in such a case, be omitted from any correspondence or reports. The aim of this study is to elucidate how patients experience pain, and the end goal is to improve patient experiences and our understanding of how patient expresses pain and discomfort.

### Community

This study poses no risk to the community of Mitchells Plain.

Ethics approval will be obtained from Stellenbosch University Health Ethics Research Committee (HREC). Thereafter, facility approval will be applied for so that data can be collected at Mitchells Plain Hospital.

## Limitations and Strengths

### Limitations

The study will be looking at a single centre, with potentially similar demographic characteristics only.This may limit external validity of the study. The argument of the investigators however, is that the demographics of the study population is a good representation of the broader community of the Western Cape.

### Strengths

There is a paucity of literature currently available regarding pain or anxiety with regards thoracostomy tube management. This study will hopefully create the basis for further research. Despite being purely qualitative in nature, the study may help guide further research into the development of pain assessment tools that can be used in a South African context.

## Data Dissemination Plan

It is anticipated that a publication in a peer reviewed journal will be produced, aimed at an audience in a LMIC setting. Ideally, it will create general awareness regarding the adequacy or inadequacy of our current analgesic practises with tube thoracostomies in an emergency centre. Information from this study could be used to develop a pain assessment scale applicable to the South African setting. The results of the study will be shared with the staff at

Mitchells Plain Hospital and the University of Stellenbosch. Results will also be shared with fellow emergency clinicians in order to improve their practise.

## Project Timeline

The study shall be completed in six months from the time of approval from the University of Stellenbosch Human Research Ethics Committee and the Western Cape Health Research Committee.

*Table 2: Project Timeline*

| *2018* | **Jan** | **Feb** | **Mar** | **Apr** | **May** | **Jun** | **July** | **Aug** | **Sep** | **Oct** | **Nov** | **Dec** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *EMDRC* | | | | | | | X | | | | | |
| *Ethics* | | | | | | | | X | X | X | X | X |
| *Hospital Permission* | | | | | | | | | | | | |
| *Data Collection* | | | | | | | | | | | | |
| *2019* | *Jan* | *Feb* | *Mar* | *Apr* | *May* | *Jun* | *July* | *Aug* | *Sep* | *Oct* | *Nov* | *Dec* |
| *Ethics* | | | *X* | | | | | | | | | |
| *Hospital Permission* | | | | *X* | *X* | | | | | | | |
| *Data Collection* | | | | | *X* | *X* | | | | | | |
| *Data Analysis* | | | | | *X* | *X* | *X* | | | | | |
| *Writeup* | | | | | | | | X | X | | | |
| *Submission* | | | | | | | | | | X | | |

## Resources and Budget

Resources required:

Hardware: Laptop, Printer, Audio recorder / Dictaphone

Software: NVivo version 12; Microsoft Word (Microsoft Office Suite);

Database access:

- MPH OpenText ECM Electronic patient folder database

Facility access: Mitchells Plain Hospital

The project will be self funded by the primary investigator.

*Table 3: Budget*

| **Budget** | |
|---|---|
| **ITEM** | **COST (ZAR)** |
| **Consumables and Services** | |
| Materials and Supplies including stationery | 500 |
| Specialised Services - Data Transcription<br>(Approx. R10 per minute for 240 minutes) | 2400 |
| Office supplies and printing for data collection | 100 |
| Office supplies and printing for report write up | 100 |
| Audio recorder | 1 500 |
| **Research travel** | |
| Travel to and from facility | 200 |
| Travel to and from university | 200 |
| | |
| **TOTAL** | **5 000** |

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# Addendum 4- HREC approval letter


**Approved**

**Response to Modifications**

01/04/2019

**Project ID #**: 8417

**HREC Reference #:** S18/10/205

Title**:** A qualitative exploration of the language and expression of pain in a Cape Town Emergency Centre

Dear Dr Muhammad Kajee,

The **Response to Modifications** received on 11/03/2019 19:14 was reviewed by members of the **Health Research Ethics Committee (HREC)** via Minimal Risk Review procedures on 01/04/2019 and was **approved.**

**Please note the following information about your approved research protocol**:

Protocol Approval Period: **01-Apr-2019 to 31-Mar-2020**

Please remember to use your HREC reference number (S18/10/205 ) on any documents or correspondence with the HREC concerning your research protocol.

Translation of the consent document/s to the language applicable to the study participants should be submitted.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from student applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

**After Ethical Review:**

Please note a template of the progress report is obtainable on https://applyethics.sun.ac.za/Project/Index/11825 and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

**Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel:+27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: https://applyethics.sun.ac.za/Project/Index/11825 If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Sincerely,

Melody Shana,

Coordinator

Health Research Ethics Committee

*Federal Wide Assurance Number: 00001372*

*Institutional Review Board (IRB) Number: IRB0005239*

*The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part*

*46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2015 (Department of Health).*

**INVESTIGATOR RESPONSIBILITIES**



**Protection of Human Research Participants**

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

- Conducting the Research: You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your coinvestigators and research staff involved with this research.
- Participant Enrolment: You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.
- Informed Consent: You are responsible for obtaining and documenting effective informed consent using **only** the HREC approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.
- Continuing Review: The HREC must review and approve all HREC approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur.** If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC Office immediately.
- Amendments and Changes: If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.
- Adverse or Unanticipated Events: Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HREC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating

  Procedures
  www.sun25.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package.
  All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

- Research Record Keeping: You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years; the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC.
- Reports to the MCC and Sponsor: When you submit the required annual report to the MCC or you submit a required report to your Sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.
- Provisions of Emergency Medical Care: When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognized as research nor will the data obtained by any of such activities be used in support of research.
- Final Reports: When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.
- On-Site Evaluations, MCC Inspections, or Audits: If you are notified that your research will be reviewed or audited by the MCC, the Sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

## Addendum 5- NHRD approval letter


Health Impact Assessment Health Research sub-directorate
Health.Research@westerncape.gov.za tel: +27 21 483 0866: fax: +27 21 483 9895 5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001 www.capegateway.gov.za)

**REFERENCE: WC 201904 002 ENQUIRIES: Dr Sabela Petros**

University of Cape Town

Anzio Road

Observatory

Cape Town

7925

For attention: Dr Muhammad Shaheen Kajee, Dr Heike Geduld, Dr Clint Hendrikse

Re: A qualitative exploration of the language and expression of pain in a Cape Town Emergency Centre

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following person to assist you with any further enquiries in accessing the following sites:

| | | |
|---|---|---|
| Mitchells Plain Hospital | Dr Jacek Marszalek | 021 377 4779 |

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.

2. By being granted access to provincial health facilities, you are expressing consent to

provide the department with an electronic copy of the final feedback (annexure 9) within

six months of completion of your project. This can be submitted to the provincial Research

Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report

(Annexure 8) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

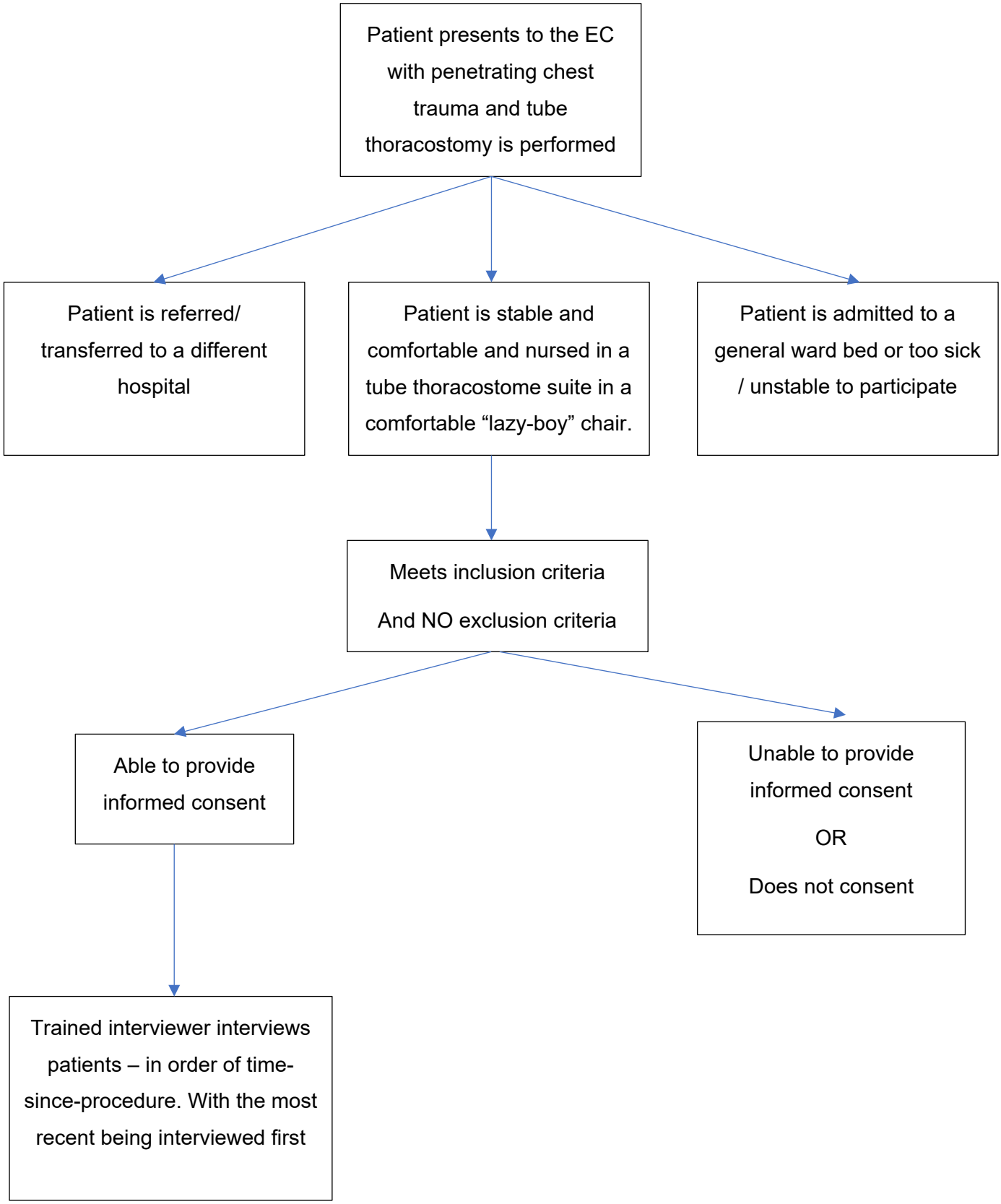
Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

**DATE:** 2_9-04-2015

# Addendum 6- Enrollment flowchart



# Addendum 7- Demographic Data Collection Sheet

Interview Number:

Patient Name:

Folder Number:

Age:

Sex:

Racial Group:

Home Language:

Other Languages Spoken Fluently (if any):

Highest Level of Education:

Days post thoracostomy:

# Addendum 8: Consent form

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jou kennisvennoot • your knowledge partner

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT**: A qualitative exploration of the language and expression of pain in an emergency centre

**REFERENCE NUMBER:** S/18/205

**PRINCIPAL INVESTIGATOR:** Muhammad Shaheen Kajee

**ADDRESS:**

Division of Emergency Medicine
Office No 5029
Education Building
Faculty of Medicine and Health Sciences
University Stellenbosch
Tygerberg Campus
PO Box 241
Cape Town 8000

**CONTACT NUMBER:** 083 647 7111

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care

to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

**This study has been approved by the** Health Research Ethics Committee at Stellenbosch University **and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.**

**What is this research study all about?**

It will focus on how patients express their pain in the Emergency Department. It will be conducted at Mitchell's Plain Hospital where patients who have chest injuries and have had chest tubes placed will be asked about their experience. Hopefully, we will be able to use the results to guide further research in the field and improve doctors understanding of a patient's pain- so that patients like you can have a better experience.

**Why have you been invited to participate?**

You have been invited to participate, as you have recently had a chest tube placed in hospital.

**What will your responsibilities be?**

If you agree to take part in this study, you will be asked to participate in a once off interview lasting 5-20 minutes at some stage during your admission to hospital. Your responses will be recorded anonymously.

**Will you benefit from taking part in this research?**

There is no direct benefit to you by participating in the study. However, It will help doctors understand future patient's pain experience better.

**Are there in risks involved in your taking part in this research?**

The are no major risks to participating in the study. There is a small chance that confidentiality may be breached, but the researchers have taken great steps to prevent this by anonymising all data immediately and storing all information on password protected devices. No data will be shared with

any one not directly linked to the study. Participation will only take a small amount of time. If at any stage you become uncomfortable, you are welcome to withdraw, at no disadvantage to you.

**If you do not agree to take part, what alternatives do you have?**

Participation is voluntary. You have the option to not participate. You will not be penalised, in any way by deciding to not participate.

**Who will have access to your medical records?**

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by not documenting or saving your name, folder number or any other personal Identifying information. All interviews will be completely anonymous, and information recorded will only be known to the primary investigators. Once completed, the interviews will be deleted. When the findings of the study are published, all interviewee personal information will remain anonymous

**What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

There is no risk of physical injury. Emotional support and counselling will be offered to patients experiencing significant anxiety. This will be done by the treating clinician, and their team with assistance from the operational manager at Mitchells Plain Hospital, and an in-house clinical psychologist. In the event that a potential participant is experiencing significant pain at the proposed time of the interview, a clinician or senior nurse will be informed, and the interview will be cancelled or postponed, depending on the circumstances.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

**Is there any thing else that you should know or do?**

- You can contact Muhammad Shaheen Kajee at tel 083 647 7111 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

- You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ……..…… agree to take part in a research study entitled ***A qualitative exploration of the language and expression of pain in an emergency centre***

**I declare that:**

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2019.

Signature of participant Signature of witness

**Declaration by investigator**

I *(name)* ……..…… declare that:

I explained the information in this document to ……..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..……. on (*date*) ……...…….. 2019.

Signature of investigator Signature of witness

# Addendum 9: Interview Schedule

| English |
| --- |
| 1. Tell me about the pain that you experienced when the tube was placed.<br>- How strong is/was your pain?<br>Prompt 1: What do you remember of the procedure?<br>Prompt 2: Did you complain about the pain?<br>Prompt 3: Did you ask for additional pain medication? |
| 2. We heard from some patients that they feel it is difficult to describe their pain to the doctor.<br>- How is that for you? |
| 3. Have you seen the number systems for pain? *(addendum 9)*<br>*On this scale, 0 is no pain at all, and 10 is the worst pain you can possibly imagine.*<br>- on the number system below, what number was your pain when the tube went in?<br>- How would you describe a 1/10 pain?<br>- How would you describe a 5/10 pain?<br>- How would you describe a 10/10 pain? |
| 4. Have you seen the face systems for pain? *(addendum 9)*<br>- what “face” was your pain when the tube went in?<br>- How would you describe a pain for the first “face”?<br>- How would you describe a pain for the crying “face”? |
| 5. Do you have any comments about telling your doctor about pain? |

# Addendum 10: Pain Scales